

Engagement of people with long term conditions in health and social care research

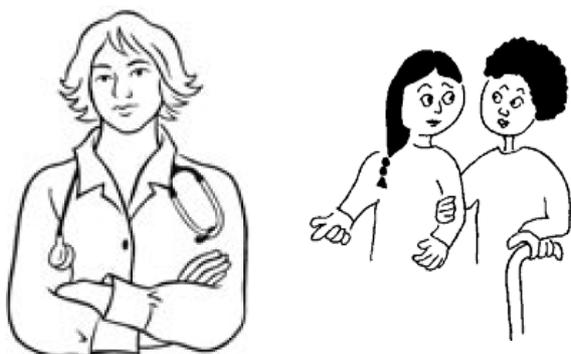
*Barriers and facilitators to capturing the views of
seldom-heard populations*

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Involving everyone in research about health and social care.



This summary tells you about some work that was done to find out about including 'seldom heard groups' as participants in research about health and social care.



'Seldom heard groups' are people who often get left out of research. For example:

- people with disabilities,
- people who have a long-term illness and
- people from black and minority ethnic communities.



Research is finding out things.

This Report tells you what we found and what could be done to make sure that no one gets left out of research.

About the Report



Researchers at the University of Kent and University of Oxford worked on this Report.

We wrote it for the Department of Health.

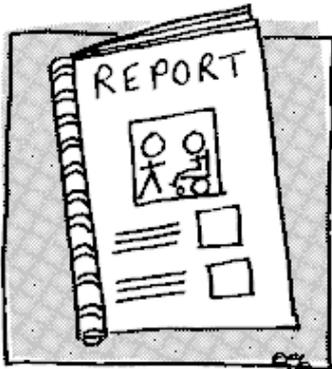


We wanted to find out who gets left out of research about health and social care.



We also wanted to know why they get left out and what can be done to make sure that everybody can be included in research.

How we wrote the Report



We looked at what research had been done. We read lots of reports that talked about including people in research about health and social care.



We made notes about the reports. We used our notes to find information about how people take part in research.

This is called a 'review'.

What we found out



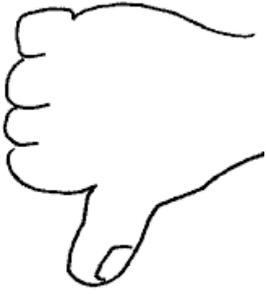
The reports told us about research with lots of different groups of people:

- people with learning difficulties,
- older people,
- people with mental health problems and
- black and minority ethnic communities.

We found many reasons why some people get left out of research



1. Sometimes researchers think that some people are not able to take part in research and decide to leave them out.



2. People can also be left out because researchers do not use the right research methods.



Research methods are ways of finding out things from people. For example:

- giving people written questions,



- talking to people, or



- watching people doing things.



Sometimes researchers use research methods that are too difficult for people. For example people with learning difficulties can find it difficult to fill in forms or answer difficult questions.



3. Researchers often contact people through services. People who do not use services get left out.



Sometimes services are not very helpful and they do not tell people about the research. Or they only tell some people about it but not others.



4. Sometimes people do not want to be involved in research. For example they are too busy or too ill to take part.

Or they are just not interested.



5. Some people can find it more difficult to take part in research. For example:

- people who need a lot of help,
- people who may not be able to speak, or
- people who may not be able to understand and speak English well.



These people need more help to take part in research. But sometimes they do not get enough help and they get left out.



6. Sometimes researchers are not very good at telling people about their research. They do not give enough information to people. People then find it hard to say yes or no to taking part in research.



7. Sometimes people find it difficult to get to the meeting with researchers. Some people need help to get around. If they do not get help, they are left out of research.

Ways to make research better for everyone



People who use health and social care services should be involved in research from the beginning. For example they can advise researchers about

- how to tell people about the research,
- what questions to ask and how to ask them.



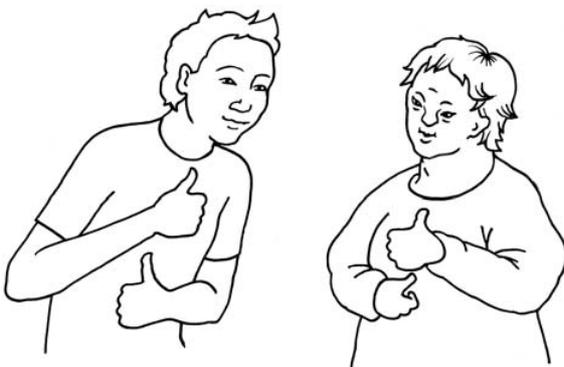
Researchers should tell people about the research in a way that is easy to understand.

For example they should:

- talk to people,
- give people easy read information or
- give information in other languages.



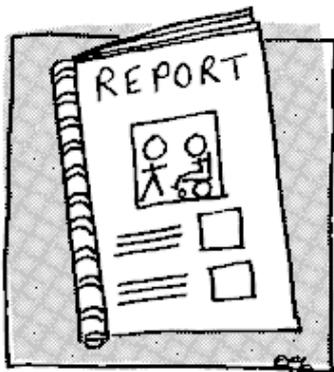
Researchers should help people to take part in research. They must make sure that it is easy for everyone to take part in research.



They should use the research methods that are best for the people who will take part. They must find ways to include everyone in research.



Researchers must learn about the needs of different people. They must learn how to make information easy to understand. For example use easy read words, pictures or sign language.



In the reports researchers should say more about who took part in the research. This would help us know more about who got left out of the research.

If you would like a printed copy of this summary, please e-mail Clara Heath – c.l.heath@kent.ac.uk

The Policy Research Unit in Quality and Outcomes of person-centred care (QORU) is a collaboration involving researchers in health and social care from the Universities of Kent, Oxford and the London School of Economics (LSE) funded by the Department of Health.

Our aim is to improve the quality of health and social care of people with long-term conditions through generating high-quality evidence about need, quality and outcomes of person-centred care.

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